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PATRICK MALONE
ASSOCIATES

Better Healthcare Newsletter from Patrick Malone

Dear Jessica,

Must every silver lining come with a drenching cloud? Medicine has made major advances in treating fearsome conditions like cancer, HIV-AIDS, congenital heart disorders, and infectious diseases. This progress has won deserved acclaim, edging some care givers to incautious use of a problematic four-letter word: *cure*.

Less known, however, are some later- and late-developing health challenges for patients once told they were free of what have been killer maladies. Some of the new and potentially big problems arise from the very

IN THIS ISSUE

BY THE NUMBERS

17 million

Estimated number of Americans who have survived a serious bout of cancer. That figure is expected to increase to 22 million by 2030.

lifesaving therapies that patients earlier received.

And while these unanticipated ills took time for patients and doctors to recognize and understand, they also offer an unpleasant reminder: Understatement and caution can be a best path for doctors, hospitals, and medical researchers. Patients also may wish to be wary of ways that Big Pharma and doctors talk about treatments and outcomes.

Optimism, hope, and traditional faith can play key roles in bolstering patients' well-being. But when it comes to your health, being fully informed about the short- and long-term realities of your needs can be vital. Here are reasons why skepticism — but not cynicism — also can matter to you and your loved ones when dealing with serious health issues. *

*If you see colored type in this newsletter, it indicates the presence of a hyperlink that you may wish to click on for further information.

When 'disease-free' isn't really free: Serious conditions may recur or even lead to yet more health ills

In the second decade of the 21st century, it can be too easy to forget the deadly fear that patients and their families confronted not that long ago with certain diagnoses.

With polio, for example, the worst outbreak of the disease in this nation's history in 1952 infected 58,000 people, killing more than 3,000 and paralyzing 21,000 — mostly children, Time magazine reported, adding: "Parents were haunted by the stories of children stricken suddenly by the [polio's] telltale cramps and fever. Public swimming pools were deserted for fear of contagion."

While many stricken with polio recovered after only mild illnesses, thousands more were hospitalized. Polio patients suffered paralysis and were wheelchair- or brace-bound. Some had to spend time inside the diabolical-looking breathing-assistance device known as the iron lung.

60%

Percentage decline between 1987 and 2005 of childhood deaths in U.S. due to congenital heart defects. Experts say the greatest successes were registered with what once were considered the toughest cases.

$30,000+

Cost that HIV-AIDS patients say they must pay annually for anti-viral cocktails that keeps their illness in check, meaning it is a chronic but costly condition.

250,000

Estimated number of Americans, who, struck earlier by polio, may suffer decades later from progressive and debilitating post polio syndrome.

QUICK LINKS

Our firm's website

Read an excerpt from Patrick Malone's book:

The life you save

Nine Steps
to Finding the Best
Medical Care —
and Avoiding the Worst

In the 1940s, 50s, and even decades later, other young patients and their parents lived in dread of congenital heart defects. Though surgeons experimented in dire circumstances with procedural innovations, the task of repairing complex deformities in the beating hearts and flowing blood vessels of tiny, fragile patients remained daunting. Thousands of babies died, despite valiant medical efforts.

It was just a blink ago — in the 1980s — that HIV-AIDS began to explode as a killer, becoming by 1995 the leading cause of death for Americans ages 25 to 44. The viral infection claimed hundreds of thousands of ordinary lives as well as those of the creative elite in entertainment, the arts, sports, and high culture. HIV-AIDS also led to a second "sexual revolution," compelling Americans to reconsider their practices in an epidemic era.

But wait: Medical science defeated these nightmarish conditions, right?

- The introduction of Jonas Salk's vaccine halved polio infection and deaths within years of its 1954 debut. By 1962, the number of reported cases had dived to 1,000 or so, and polio is now considered eradicated in this country. This disease, by the way, offers a formidable argument for the benefits of vaccinations — a topic in counter-factual dispute these days.

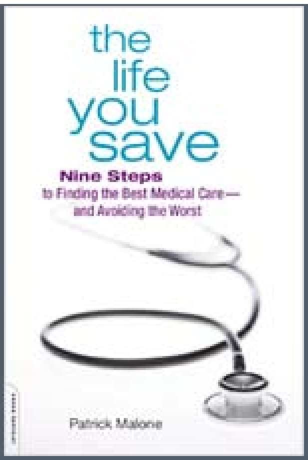
- Surgical advances, notably progress with open-heart procedures and increasingly sophisticated devices to assist with them, have led to a standard of care that dropped childhood deaths from congenital heart defects 60% between 1987 and 2005. More than 1 million adult survivors attest to the effectiveness of the surgical repair of these once-fatal birth defects.

- Although it still killed almost 16,000 Americans in 2016 and more than 1 million carry the infection, HIV-AIDS — with the development of powerful anti-viral drugs — now is considered a chronic and manageable disease, especially with early diagnosis and sustained treatment.

Could modern medicine lay claim to sunnier success stories than these? Well, here come some of those doggone dark clouds.

Decades after defeating polio, specialists are struggling with a slow-moving complication, described by the March of Dimes as post-polio syndrome, or PPS, affecting as many as a quarter-million Americans who once were infected with the disease:

"The main symptoms of PPS are new progressive muscle weakness that



the life you save
Nine Steps
to Finding the Best Medical Care—and Avoiding the Worst
Patrick Malone

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Read our Patient Safety Blog, which has news and practical advice from the frontlines of medicine for how to become a smarter, healthier patient.

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PAST ISSUES

Why older patients may need to be wary about aggressive medicine
Marijuana may not be a shrieking menace, but it has real harms for young and old, and benefits are murky.
Beware: Quest for beauty can come at too high a cost
Let's praise medical malpractice lawsuits
All about vaccines: What you and your family need and why

You Can Eat This... But

gradually worsens, together with severe fatigue and pain in muscles and joints. It is often accompanied by decreased muscle endurance during activities. No cure exists for PPS. Doctors advise patients to curtail physical activities and take rest periods during the day, including during working hours. Many doctors also advise more severely affected patients to use wheelchairs part-time or full-time, even if they can walk without them. As many as 40% of polio survivors may get PPS, according to some estimates."

As for those young heart patients, as they become seniors, many find they must return for complex operations for their condition — sometimes going back to the pediatric hospitals that performed their surgeries decades before. As the Stanford Medicine news service reported:

"Some patients' childhood surgical repairs were initially judged so successful that they never expected to return to a cardiologist … In other cases, the first surgery was so unusual and risky that the surgeon discouraged the patient from undergoing further operations. But most adults with repaired congenital heart defects are not cured, doctors have learned. As their discipline has matured, cardiologists have honed their understanding of how to help patients … navigate the risks of living with lingering heart problems … [doctors also have] learned how congenital defects interact with cardiovascular problems people acquire with age. The doctors draw on knowledge from both pediatric and adult cardiology to diagnose the current condition of patients' hearts and provide lifestyle counseling, medical management and interventional and surgical treatments."

As for those with HIV-AIDS, patients are discovering the disease ravaged their bodies in ways that affect them as they age, and potent drugs they received and continue to take may have long-term side effects. The federal Health and Human Services department has described some of these issues:

"While effective HIV treatments have decreased the likelihood of AIDS-defining illnesses among people aging with HIV, HIV-associated non-AIDS conditions are more common in individuals with long-standing HIV infection. These conditions include cardiovascular disease, lung disease, certain cancers, HIV-Associated Neurocognitive Disorders (HAND), and liver disease (including hepatitis B and hepatitis C), among others. In addition, HIV appears to increase the risk for several age-associated diseases, as well as to cause chronic inflammation throughout the body ... associated with … health conditions, including cardiovascular disease, lymphoma, and type 2 diabetes … HIV and its treatment can also have profound effects on the brain. Although AIDS-related dementia, once relatively common among people with HIV, is now rare, researchers estimate that more than 50% of people with HIV have HAND, which may include deficits in attention, language, motor skills, memory, and other aspects of cognitive function that may significantly affect a person's quality of life. People who have HAND may also experience depression or psychological distress."

With cancer, survivors must stay

Why Would You?

Looking Ahead: Preparing for Long-Term Care

Managing Chronic Pain: It's Complicated

Secure Health Records: A Matter of Privacy and Safety

Standing Tall Against a Fall

More...

vigilant

Because cancer is the No. 2 killer of Americans, trailing only heart disease, the significance of medical advances and survivorship are major. As the Wall Street Journal noted in a recent special report:

“There are growing numbers of cancer survivors. Nearly 40% of men and women will develop an invasive cancer in their lifetimes, with men at slightly higher risk. But thanks to medical advances in detection and treatment, there are close to 17 million cancer survivors in the U.S. — and with an aging population, that number is expected to rise to about 22 million by 2030.”

The National Cancer Institute reported this year:

“Ten of the 19 most common cancers in men showed decreases in mortality: leukemia, melanoma, non-Hodgkin lymphoma, and cancers of the colon/rectum, larynx, lung and bronchus, stomach, bladder, esophagus, and kidney. [And] 13 of the 20 most common cancers in women showed decreases in mortality: leukemia, melanoma, non-Hodgkin lymphoma, and cancers of the bladder, breast, cervix, colon/rectum, esophagus, gallbladder, kidney, lung and bronchus, ovary, and stomach. Melanoma had the greatest decrease in mortality.”

Treatment advances have made many types of cancer, which once had poor outcomes, into chronic and manageable conditions. At the same time, the Wall Street Journal reported that for cancer survivors:

“They are left with new health issues often caused by the treatment itself, such as damage to the heart and other organs, or worsening high blood pressure and diabetes. Studies show many struggle with depression, fatigue and nagging fear that the cancer will return. Sexual function and personal relationships may suffer. Compounding it all, survivors often feel alone and adrift as they face those challenges. According to a new survey of cancer survivors by the nonprofit National Coalition for Cancer Survivorship, few feel very prepared for the transition to posttreatment, nor informed about how to manage their health going forward. Their oncologists are focused on treating new cases, and their primary-care doctors have neither the time nor expertise to deal with the complexities of survivor needs.”

Patients may be staggered when, decades after their original diagnoses and treatment, they consult with specialists and find they may be dealing with a recurrence of their cancer or other types of the disease. As the newspaper reported:

“In one case, a patient who had received radiation for a brain tumor 30 years earlier was treated by a primary-care doctor for what was assumed to be a recurrent infection. In fact, it was a sinus tumor caused by the long-ago radiation.”

The Wall Street Journal also cited the experiences of Dennis Patterson, a professor of law and philosophy at Rutgers University, who was originally treated for testicular cancer in 2001, reporting:

“Testicular-cancer patients must be followed carefully for possible recurrence, long-term side effects of treatment, and new cancers, with specific screenings such as tests that look for certain tumor markers … Eight years later, during a follow-up appointment, Patterson says, his oncologist … noticed his spleen was enlarged, and follow-up tests found a rare form of lymphoma, which was successfully treated with an immunotherapy drug and surgery to remove his spleen. Then, two years ago, during another follow-up visit, [his oncologist] noticed his levels of PSA — for prostate-specific antigen — were slowly rising. Referred to [a] urology department for further evaluation and management, he was diagnosed with prostate cancer, and is pursuing a strategy of watchful waiting.”

Laura Landro, the author of the newspaper special report, a seasoned health care journalist, and a onetime news executive at the Wall Street Journal, knows a lot about cancer and its less-known effects from her own experience. She wrote in a separate news article how she has battled cancer for 27 years after her initial diagnosis with the blood cancer chronic myelogenous leukemia.

She underwent a difficult and painful marrow transplant with her brother as donor and chemotherapy that she and doctors thought had knocked out her cancer. It came back a decade later. With new anti-cancer drugs available, she received those, plus more transplant cells from a brother. That knocked the cancer down for a few more years. It returned again, and yet another sibling cell transplant has helped put out detectable cancer for Landro for a dozen years. She observed:

“…I've seen for myself that cancer is a wily adversary and often finds its way around obstacles, so I'm never going to drop my guard. I know I am at risk for other cancers and the importance of regular screening such as colonoscopy, mammograms and skin checks. Vigilance is a small price to pay for the life I got back after the transplant and the many gifts that have come my way since.”

Excellent advice.

For long-term patients, a workable way: Optimism tempered with healthy realism

As WSJ reporter Laura Landro observed, patients can have enormous gratitude for receiving compassionate care that extends their time, even if that means decades of worrying about a shadow on their lives. No one, of course, can fault doctors and medical scientists for not having a crystal ball — seeing far down the road at how those spared of one deadly condition might, in turn, be subject to others. And who wouldn't see and understand why, in tough moments of difficult care, patients would have high appreciation for doctors and nurses who buck them up during dark times.

Still, patients also are owed their fundamental right to informed consent. This means they must be told clearly and fully all the important facts they need to make an intelligent decision about what treatments to have, where to get them, and from whom. Patients' age — especially for the very young and the very old — can complicate their capacity to participate in decision making about their care. But doctors, hospitals, and loved ones may need to step up to ensure that the patients get to make the important calls, as much as they appropriately can.

Doctors may do a disservice to patients by failing to be clear about the difficulties associated with a treatment path or big challenges for those who live through conditions that cause major damage. The financial toll of chronic diseases — notably the current crushing cost for cancer care, the vicissitudes of giant medical bills, and the incessant battles with health insurance companies — weighs heavily on patients and their loved ones.

The treatment of those with major illness or injury may be messier still due to costly medications and therapies with high uncertainties. Cancer, unfortunately, is too frequently misdiagnosed. With serious conditions, patients may benefit even more from seeking out a second opinion on their case. As always, Big Pharma and its interests may play an unhappy role in controversies about patient care. (See sidebar).

Cardiologists and oncologists, for example, have tussled recently over the toxicity of breast cancer drugs and how much patients should be told about how the meds may damage the heart and lead to long-term cardio needs. This argument not only persists but has been extended beyond women and breast cancer care. Landro reported that "chemotherapy plus radiation was long the standard treatment for a type of Hodgkin's lymphoma. But as evidence emerged that radiation can lead to new cancers and other complications, doctors have reduced or in some cases eliminated radiation as studies suggest chemotherapy alone improves the rate of overall survival for certain patients.”

Patients with HIV-AIDS have launched lawsuits against makers of drug “cocktails” that are central to their care. They have accused firms of keeping the prices too high, at an estimated $30,000 a year. The makers’ patent gamesmanship, for example, may have kept researchers from finding alternatives with far fewer side effects than current meds have, plaintiffs have claimed.

But even as drug makers and clinicians seek to improve treatments for major conditions, reducing medications’ harsh regimens and debilitating side effects, surgeons and radiation experts find themselves under fire for the cost and effectiveness of their therapies. As the Wall Street Journal reported, “A recent study found that women who had minimally invasive surgery for cervical cancer had higher odds of recurrence than those who had traditional open surgery.” Indeed, a growing body of research is raising serious concerns about the expense and effectiveness of minimally invasive surgeries involving robotic devices in treating problems in the male and female reproductive systems. As for radiation treatments, the Choosing Wisely initiative has identified at least 10 treatments for serious conditions that both patients and physicians should look at with wariness, including reflexive use of so-called proton beam treatments. Hospitals may advocate for this high-level care after spending significant sums for bright, shiny equipment that promises to do more and inflict less harm.

Landro also offered a warning about another much-promoted cancer therapy, reporting: “Novel immunotherapy drugs, which harness the immune system to find and eliminate cancer cells, hold great promise for some cancers, but there are still many unknowns about long-term effects and recurrence risks.”

If patients and their loved ones can be clear-eyed about their situations when dealing with major conditions, they may realize that their medical histories can determine their medical futures.

Landro reported that survivors of serious health conditions may need to seek out specialists, experts not only versed in a specific disease like cancer but also knowledgeable in how, over the duration, it may change and harm the body, resulting in other illnesses and conditions. This may mean years of regular check-ups with invasive and costly testing. It may mean taking medications for long spans, dealing with unpleasant side effects. Patients, though they have shed the specter of one life calamity, may feel burdened by the threat of its return — or of yet other problems.

For young patients, the issues can be substantial. As the Wall Street Journal reported of youthful cancer survivors:

“Thanks to advances in treatment, more than 83% of children treated for cancer can expect to survive five years or longer, compared with 58% in the mid-1970s, according to the National Cancer Institute. Yet because cancer treatment can damage organs, impede growth and learning ability, and lead to later cancers, patients need lifelong support and follow-up. And the problems aren't just medical. Young survivors have a daunting medical history to keep track of as they grow and move away from or outlive the doctors who originally treated them.”

Stanford Medicine, reporting on Sang Hee Yoon, a 61-year-old patient who needed surgery after a major heart repair in his youth, noted that he wisely had kept up his cardiology care. His early operation had saved his life, but he had lingering chest pain and breathing troubles at altitude. As he aged, surgeons told him that a problematic heart valve, repaired before, was failing and needed replacement. He underwent a four-hour operation and says he feels better than ever.

The stories of Yoon, Landro and others contain valuable guidance for all patients. It’s important to look with optimism — tempered with realism — toward a better future. Sustained, informed care is important, as is getting and keeping copies of health records. Patients also may benefit greatly by having loved ones and friends accompany them and help them understand complicated medical care. Indeed, cancer survivors, for example, have clamored for clinicians to offer them more detailed information about treatments, short- and long-term. They have insisted in surveys and research that an under-emphasized aspect of their care comes from support groups with patients who have experienced what they have and can offer practical, useful coping ideas and mechanisms. (See sidebar about issues with the groups).

For the individual patient, resilience is important. Stanford Medicine reported that Yoon defied conventional wisdom after his youthful heart surgery and married and raised a family. He became a pastor. Landro wrote about Marissa Vickers, 26, “who began radiation and chemotherapy treatments at age 18 [at the University of California, San Francisco] for Ewing's sarcoma, a type of cancer that grows in bones or the soft tissue around them.” Vickers kept up a cancer care regimen that started with three-month checkups that then moved to six-month check-ins and converted to a survivor program at five years. She has become a pediatric nurse in the meantime and hopes to receive further training to specialize in cancer care for kids. She refuses to be defined by her illness, Landro reported:

“[Vickers] … believes surviving cancer has changed her life for the better in unexpected ways — without it, she never would have moved to San Francisco, where she met her husband, or had her children. ‘It made me face my own mortality, realize what's important and not wait for tomorrow,’ Ms. Vickers says. In addition to making her cherish activities like swimming and igniting a passion to swim for the cause of cancer research, it led her to a rewarding career ‘and purpose-filled life making other people's treatment journeys better,’ she says. ‘Although I wish all these things could have happened without cancer and chemo, I wouldn't change it now if I could.’"

Landro herself echoes the experiences of those she has written about, arguing that drastic and recurrent illness can be life-changing in positive ways, too:

“My experience led me to change the focus of my career in journalism from the media and entertainment beat to health and medicine, with the aim of informing readers about the things they needed to know to empower themselves as patients. I wrote a book that hopefully helped others facing a cancer diagnosis. And my husband and I have supported research … perhaps one of the most rewarding things a former cancer patient can do to help advance the science that saved them, and much needed at any level."

Those are silvery thoughts. As we all head into the high season of giving thanks and celebrating family and all the heaven-sent gifts we enjoy in our various ways, here's hoping that you and yours never experience severe conditions and that you have terrific health in the rest of 2019 and beyond!

For Big Pharma, profits first, patient needs after

Big Pharma is central to the 21st century treatment of serious conditions. But consumers would be well advised to understand that the industry seeks to maximize profits for its shareholders, even ahead of patient care, including for those dealing with dire conditions.

Elisabeth Rosenthal, who was trained as a physician, has reported on health care policy for the New York Times, and now heads the nonpartisan Kaiser Health News service. Ms. Rosenthal made these the first two of her multiple rules to explain how dysfunctional the U.S. system has become, as described in her book, *American Sickness: How Health Care Became Big Business and How You Can Take It Back*:

1. More treatment is always better. Default to the most expensive option.
2. A lifetime of treatment is preferable to a cure.

She explained the implications of these points to NPR host Terry Gross:

Bonding together: the key for a tough journey

The experience of coping with a serious health condition can be frightening, debilitating, and lonely. Besides significant concerns like one's physical well-being, family and work life, and financial nightmares, patients say they find it tough to even talk with others who have not shared their ordeals.

As a patient described it in a major survey by the National Coalition for Cancer Survivorship:

"I would like to meet more cancer survivors. I feel now that I am a different person and that no one understands what I've been through. Most people think that because you survived, that you are great and not in need anymore. It would be helpful to have some friends who have gone through the same journey."

Hospitals and treatment centers emphasize the importance of such connections and often can assist patients in finding support groups and other resources for their longer-term care and recovery. But patients in the coalition survey also said that doctors may not be the providers of such help, “Well, you know, you've got to look at every medical problem from two sides — what's right for health care and what's good for business. And you have to remember, we've trusted a lot of our health care to for-profit businesses. And it's their job, frankly, to make profit … So, if you're a pharmaceutical manufacturer and you have a problem like diabetes, for example, if I invented a pill tomorrow that would cure diabetes, that would kill a multibillion-dollar business market. It's far better to have treatments. And, you know, sometimes really great treatments, very effective treatments, so that's good. But you kind of want the treatment to go on for life. That's much better than something that will make the disease go away overnight.”

Harsh though that appraisal may seem, it may be worth keeping in mind as drug makers pressure politicians and the regulators they oversee to speed up the approval process for prescription drugs. The makers insist that innovations must be raced to the market to benefit patients. But critics say that Big Pharma’s haste will lay waste to the scientific rigor, including randomized clinical trials, that safeguards the public from flawed and dangerous products.

The drug industry, in effect, hopes to change the common-sense ways we think and even talk about serious health concerns. Big Pharma has convinced regulators to approve increasing numbers of drugs based not on whether they improve the quality of patients’ lives or sustain them. Instead, they propose drug approvals using surrogate measures, markers, or end points. They may be faster and easier to build data on. Cancer drugs, for example, can get the green light from regulators because they show in tests that they may shrink tumors, or delay their growth. That doesn’t mean that patients who take these drugs — with their sky-high prices, considerable side effects, and potential risks — live better or longer. Some diabetes medications now target lower hemoglobin A1c (HbA1c), a measure of average blood-sugar levels over the preceding three months. But just because they hit that mark doesn’t mean they’re more beneficial than existing meds for living better/longer, particularly because the new drugs may have harmful heart effects.

Eric Topol, a doctor and faculty member and research executive at the noted Scripps Research center in Southern California, took to Twitter recently to note a news story based partly on a drug-industry information source. The data showed Americans especially as time wears on and office visits are typically brief.

The internet may beckon with online groups. But these may include problematic or troubled individuals (including illness fakers), which may complicate the lives of patients who already have enough troubles of their own.

The federal government offers some national resources. So, too, do patient advocacy groups.

But, hear this: The major groups, while well-known and important for patients with special needs, may be unwinding their own good works with their own sketchy funding choices. As the New York Times reported:

“A new study has found that more than 80% of [patient advocacy groups] accept funding from drug and medical-device companies. For some groups, the donations from industry accounted for more than half of their annual income, and in nearly 40% of cases, industry executives sit on governing boards, according to the study, which is published in The New England Journal of Medicine. Nearly ‘nine out of every 10 are taking money,’ said Dr. Ezekiel J. Emanuel, an oncologist and vice provost at the University of Pennsylvania. He is one of the authors of the study, which looked at the top 104 nonprofit patient advocacy groups that reported more than $7.5 million in annual revenues for 2014. ‘I think that is not well known — I think that is a shock.’”

The issue is important for patients with serious conditions, the newspaper reported:

“[P]atient groups often do not disclose that they take industry funds when they testify before Congress or government agencies, or when they disseminate educational information to patients. Many have also been silent on the issue of rising drug prices, even as the issue has enraged patients, who have been increasingly exposed to the prices that pharmaceutical companies set as insurers have asked them to pay a greater share of their drug costs.”

One patient-data-sharing group that I featured in my book, "The Life You Save," is called Patients Like Me. It was started as a website for patients to share their own disease data and what worked and didn't work in their treatments for very serious conditions like ALS (Lou Gehrig's disease), Parkinson's, spending $100 billion on prescription drugs in 2018, with more than half of that sum ($51.4 billion) paying for six drugs common to cancer care and a third ($34.5 billion) for three medications associated with immune treatments, also often related to cancer. His post attracted dozens of replies, including from a Mayo Clinic cancer expert who observed: “Not one of these [cancer] drugs are curative. Granted some … increase the cure rates over existing therapy in subsets, that’s not where these revenues come from... It is basically year after year of profits because these drugs are taken chronically.”

Indeed, Vinay Prasad, a doctor, author, and associate professor of medicine at Oregon Health and Science University, has criticized doctors and Big Pharma for how they promote drugs and their cozy dealing, writing in an Op-Ed for Stat, a health and medical website:

"Americans are rightly furious about the high and unsustainable price of cancer drugs, which now routinely cost more than $100,000 per year of therapy. Those prices are made worse by the fact that most cancer drugs offer only modest benefits — one study put the median benefit at 2.1 extra months of life — along with the fact that expert physicians frequently recommend these drugs for off-label uses, meaning using a drug for a purpose it was not initially approved for. The House of Representatives, the Senate, presidential candidates, and even the president have floated proposals to tackle drug prices. While all contain good ideas, none address one of the elephants in the room: the experts who tell doctors how to use these medications. Expert physicians play an over sized role in cancer medicine. They write the editorials in major medical journals that can influence physicians’ prescribing practices, they give educational sessions at national meetings, and they decide what evidence is good enough for off-label use. Spoiler alert: That evidence is often weak. All of this might be fine if experts offered neutral or unbiased information, but evidence suggests they do not. One study found that 85% of the experts who wrote widely used cancer guidelines had received payments averaging more than $10,000 from pharmaceutical companies ... Research also shows that physicians who consistently put pharmaceutical money in their bank accounts are more likely to prescribe that company’s drugs. Financial conflict of interest in cancer medicine matters. The pharmaceutical industry is run by intelligent people who choose to

various cancers, and other chronic long-term issues. When I first heard about it, I was excited at the prospect for patient empowerment. I cannot vouch for it any more, as it's been "acquired" by giant health insurer United Health. I don't know if that's good or bad, but it does mean the site is now part of American corporate health care, with all the conflicts of interest that go with that.

The National Cancer Institute offers guidance about the groups on its website, advising they "can have many benefits. Even though a lot of people receive support from friends and family, the No. 1 reason they join a support group is to be with others who have similar cancer experiences. Some research shows that joining a support group improves both quality of life and survival. Support groups can: Help you feel better, more hopeful, and not so alone. Give you a chance to talk about your feelings and work through them. Help you deal with practical problems, such as problems at work or school. Help you cope with side effects of treatment."

The institute also suggests that:

"Before joining a support group, you may want to ask yourself if you're comfortable talking about personal issues. You can also think about what you hope to gain by joining one. A support group may not be right for everyone. Some people don't like to hear about others' problems. And some find that their need for a support group changes over time. If you have a choice of support groups, visit a few and see what they are like. See which ones make sense for you. Although many groups are free, some charge a small fee. Find out if your health insurance pays for support groups ... Support groups vary greatly, and if you have one bad experience, it doesn't mean these groups aren't a good option for you. You may also want to find another cancer survivor with whom you can discuss your cancer experience. Many organizations can pair you with someone who had your type of cancer and is close to your age and background."

pay physicians millions of dollars. It is hard to believe they have not calculated that this aids their bottom lines."

Recent Health Care Blog Posts

Here are some recent posts on our patient safety blog that might interest you:

- Angry women, anxious that officials were failing to protect their health, besieged a federal Food and Drug Administration hearing in the spring. That unusual outcry may have helped push regulators off their bureaucratic backsides, getting them finally to warn about risks of one of the most commonly used medical devices for women: breast implants. But will a similar gender uprising be required to quash a rising and dubious medical testing of women, the so-called “3D mammogram?” The FDA’s sudden, fast stepping on breast implants is occurring after years of inaction. Under new rules proposed by the agency, the devices’ packaging would be required to carry “boxed warnings,” the FDA’s most serious caution. The agency also would call on surgeons to step up their discussions with women about implant risks, including for rare cancers.
- If millions of young folks in the nation’s largest state seem even sunnier than before, that may be because they are getting a wee bit more needed shut eye: California has become the first state in the nation to order public schools to roll back their start times, so middle school classes generally won’t start before 8 in the morning and high school teaching doesn’t start until after 8:30 a.m. The rule — pushed by experts and resisted by parents juggling already hectic and conflicting family schedules — will be phased in over three years. It also will be accompanied by yet more research on how teens doze and how sleep can best benefit their rapidly growing minds and bodies. California’s later start to teens’ schools got a boost from groups like the American Academy of Pediatrics, the California Medical Assn., and the California State Parent Teacher Assn. They cited a growing body of research, including by organizations like the RAND Corporation, tying more sleep from later start times to adolescents’ better school performance and health.
- In the cooler, rainier autumnal weather, transportation officials may be planting the seeds of significant change for the health, safety, and ways and means that residents and visitors get around Washington, D.C. They may allow a smaller number of private companies to double the number of scooters zipping around the nation’s capital by the new year. By the spring, the devices may quadruple in number. This could mean the estimated 5,000 or more scooters in the district now would increase to 10,000 by January and to 20,000 by June. District officials say they’re responding to a spike in demand from the public for convenient ways to get around and to do so with needing to use multiple clumsy and confusing smart phone apps.
- The elite of public health organizations are up in arms about a new report from a group of international researchers who looked at red meat and its health benefits and harms, and more or less

shrugged. The new take goes like this, reported the New York Times: “If there are health benefits from eating less beef and pork, they are small, the researchers concluded. Indeed, the advantages are so faint that they can be discerned only when looking at large populations, the scientists said, and are not sufficient to tell individuals to change their meat-eating habits.” That view, of course, contradicts what public health and nutrition experts have recommended for years, and so blue-chip health outfits like the American Heart Association, American Cancer Society, and Harvard’s T.H. Chan School of Public Health condemned the researchers for supporting what now may be akin to a health heresy.

- Millions of Americans may sigh at Bertha, Barney, or Betty, or whatever they’ve nicknamed the beat-up family vehicle parked out front: “Wouldn’t it be great, if only we could afford a nicer, newer model?” A big obstacle to that wish, however, may be the increasingly costly and unaffordable health insurance they get at their workplace. New research finds that the annual premium for family coverage — forked over mostly by companies but also by workers — now averages $20,576, according to an annual survey by the nonprofit, independent Kaiser Family Foundation. Drew Altman, chief executive of the group, commented to the Wall Street Journal about the spiking burden of workplace coverage: “It’s a milestone. It’s the cost of buying an economy car, just buying it every year.” To be sure, workers don’t bear the full cost. Their employers do. And they’re groaning, too, under the growing expense.

HERE’S TO A HEALTHY REST OF 2019!

Sincerely,

Patrick Malone

Patrick Malone
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